1 Introduction

1.1 What has the Commission been asked to do?

In late 2009, the Australian Government announced that the Productivity Commission would commence a public inquiry into a long-term disability care and support scheme in April 2010. It said:

> This inquiry is an opportunity to rethink how we support people with disabilities so that they can engage with their community, get a job where possible, and live a happy and meaningful life (Sherry 2009).

The announcement followed a succession of reports that found that the current system to support people with disability and their families is deeply flawed and will increasingly be unable to meet people's needs. Examples include the 'Way Forward' report by the Disability Investment Group (DIG 2009a) and the 'Shut Out' consultation report by the National People with Disabilities and Carer Council (Australian Government 2009a). Such reports reflected continuing concerns about systemic and long-standing inadequacies in disability care and support across Australia, and the consequent impact on people with disabilities and their carers.

In its preamble to the terms of reference, the Australian Government said that it 'is committed to developing a National Disability Strategy to enhance the quality of life and increase economic and social participation for people with disability and their carers'. It noted that:

> … there remains a significant level of unmet demand for disability services which impacts upon the lives of people with disability, their families and carers. Demographic change and the anticipated decline in the availability of informal care are expected to place further pressure on the existing system over the coming decades.

It added that:

> While Australia's social security and universal health care systems provide an entitlement to services based on need, there is currently no equivalent entitlement to disability care and support services. … exploration of alternative approaches to funding and delivering disability services with a focus on early intervention and long-term care will be an important contribution to the National Disability Strategy. (terms of reference)

The Australian Government asked the Commission to consider how a national disability scheme could be designed, administered, financed and implemented. The Commission was asked to examine the feasibility, costs and benefits of replacing the current system of disability services with a new national disability care and support scheme that:

- provides long-term essential care and support
- manages the costs of long-term care
- replaces the existing funding for those people covered by the scheme
- takes account of the desired and potential outcomes for each person over a lifetime, with a focus on early intervention
- provides for a range of coordinated support options — accommodation, aids and appliances, transport, respite, day programs and community participation
- assists the person with the disability to make decisions about their support
- provides for people to participate in education, training and employment where possible.

This includes consideration of a variety of options, including a no-fault social insurance model and approaches used in other countries. The Commission was also asked to assess how these models would interact with Australia's health, aged care, informal care, income support and injury insurance systems.

1.2 Definitions and some key facts

There is no single definition of disability. Modern definitions of disability, including those drawn from the United Nations Convention on the Rights of Persons with Disabilities (adopted by the UN in 2006 and ratified by Australia in 2008), define disability as the interaction of long-term physical, mental, intellectual or sensory impairments, and attitudinal or environmental barriers that 'hinder ... full and effective participation in society on an equal basis with others'. The World Health Organisation (2009) similarly characterises disability according to the interaction between a person's body and features of the society in which they live.

This inquiry covers many issues that affect all people with disability. However, the terms of reference indicates that the scheme is intended to cover a subset of those affected by disability.

First, the terms of reference specify that the scheme should cover disability present at birth, or acquired through an accident or health condition, but not due to the

natural process of ageing. This means that the size of the relevant group is much smaller than all those with a disability. And, the numbers in this smaller group are projected to grow more slowly than those whose disability is ageing related. However, while this inquiry mainly considers people with disabilities aged under 65 years, population ageing will significantly raise the overall number of people with severe or profound disability, placing even more pressure on services, including for people who are not old. It will also affect the availability of unpaid carers.

Box 1.1 **Some definitions**

According to the Australian Institute of Health and Welfare, and as used in the Australian Bureau of Statistics (ABS) *Survey of Disability, Ageing and Carers*, 'disability' is defined as a limitation, restriction or impairment that has lasted, or is likely to last, for at least six months and restricts everyday activities. According to this definition, in 2009, just under one in five Australians reported having a disability.

The severity of people's disability varies significantly. At the more severe end of the spectrum people are classified by the ABS as having either:

- a profound core activity limitation, where an individual is unable to do, or always needs help with, a core activity; core activities are self-care, mobility and communication, and include washing, toileting, dressing and eating
- a severe core activity limitation, where an individual sometimes needs help with a core activity or task, and/or has difficulty understanding or being understood by family or friends and/or can communicate more easily using sign language or other non-spoken forms of communication.

While the above categories can be useful, as can the broader International Classification of Functioning, the appropriate definition of disability should take account of the policy context in which government is applying it and of the practical ease of identifying disability. For example, under the ABS's approach, many intellectual disabilities might not be categorised as severe or profound (reflecting the omission of learning as a 'core activity limitation'). However, in the Commission's view (chapter 3), there are strong grounds for a disability scheme to provide funded supports to people with an intellectual disability. On the other hand, some people suffering from short-lived but terminal diseases might well have severe disabilities, but governments could better support them through the health and palliative care systems.

Source: ABS (2010c); AIHW (2011a).

Second, the scheme is not intended to provide funding packages to all people with a disability, many of whom would need no or few supports, or who would get supports more appropriately from other government services. These matters are discussed in chapter 3.

Some key facts about disability

There are various measures of the number of people with the most significant needs (box 1.2). For example, among those aged under 65 years, there are around 680 000 people with a profound or severe core activity limitation (SDAC 2009), around 310 000 who have at least daily care needs (with mobility, self care and/or communication) (SDAC 2009), and about 172 000 who currently use specialist disability services (excluding Australian Government employment services) (SCRGSP 2011).

The estimates in box 1.2 are of the total number of people with severe or profound core activity limitation at a point in time ('prevalence'). Each year, there are also *new* cases of disability ('incidence'). Of the 680 000 people with severe or profound core activity limitation, about 80 000 were new cases and about 600 000 were people who acquired a disability at an earlier time. While new cases add to the numbers of people with disability, deaths and reductions in disability reduce the numbers. In many instances, people will experience temporary disability (as potentially in cases of depression, anxiety and attention deficit hyperactivity disorder), and will not necessarily require long-term care.

The health conditions of people under the age of 65 years who have a profound core activity limitation include diseases of the nervous system, intellectual and developmental disorders, mental illness, diseases of the circulatory, respiratory and digestive systems, cancers, and diseases of the musculoskeletal system (table 1.1).

Table 1.1 **Health conditions of people who have a profound core activity limitation**[a]

People under 65 years of age

Condition	*Percentage*
Intellectual and developmental disorders	15
Diseases of the nervous system	14
Diseases of the circulatory system, respiratory system, digestive system; endocrine, nutritional and metabolic disorders; neoplasms	14
Diseases of the musculoskeletal system and connective tissue	14
Mental illness	11
Autism	9
Congenital malformations, deformations and chromosomal abnormalities	6
Other mental and behavioural disorders	5
Injury, poisoning and certain other consequences of external causes	4
Diseases of the eye and adnexa; and ear and mastoid process	3
Other	5
Total	100

a Prevalence of main condition causing disability.

Source: SDAC (2009).

Box 1.2 How many people have significant needs?

While they share similar conceptual underpinnings, measures of significant disability vary markedly, depending on the data source and survey methods:

- Using the ABS Survey of Disability, Ageing and Carers, 2009 (SDAC 2009), around 263 000 people aged under 65 years had a profound core activity limitation in 2009 and 417 000 had a severe core activity limitation — or 680 000 in total.
- The ABS 2006 Census of Population identified a smaller group of people with a severe or profound core activity limitation (around 400 000 aged under 65 years in 2006), but this estimate is generally regarded as a less reliable measure than SDAC.
- Within the group of people classified as having a severe/profound core activity limitation there is a large spectrum of need for assistance. As an example, the 2009 SDAC indicates that approximately 310 000 people under the age of 65 years required at least daily assistance with one or more core activities (self care, mobility and communication). Within this 310 000:
  - about 23 per cent indicated that they needed assistance more than six times a day with at least one core activity
  - a further 24 per cent indicated that they needed assistance three to five times a day with at least one core activity
  - a further 17 per cent indicated that they needed assistance twice a day with at least one core activity
  - and a further 36 per cent indicated that they needed assistance once a day with at least one core activity.
- Usage of disability services provides other indicators of the numbers of people with the greatest need for support:
  - There were just over 265 000 people using specialist disability services under the National Disability Agreement (NDA) in 2008-09 (SCRGSP 2011). Of this 265 000, approximately 94 000 only used employment services. The NDA is directed at those whose disability was acquired before the age of 65 years.
- Around 200 000 people aged under 65 years used Home and Community Care (HACC) in 2008-09 for services such as nursing care, allied health, and the provision of aids and equipment that were not available under the NDA. People often use both NDA and HACC services, so the total number of users of NDA and HACC is not the sum of HACC and NDA services (approximately 20 per cent of people using NDA specialist services — excluding employment services — also access HACC services). Further, several people used very little HACC services (approximately one hour of care a fortnight).

Sources: ABS (2010c); DoHA (2009).

1.3 Ways of thinking about disability

Several participants drew attention to the (now very commonly expressed) social model of disability, which takes the view that 'disability' arises socially, rather than medically. In this case, disability reflects social barriers, such as prejudice, out-of-date practices, and poorly designed infrastructure. In other words, while a person may have an impairment, their disability comes from the way society treats them, or fails to support them. For example, the capacity for mobility of a person in a wheelchair is limited if buildings and transport are not easily accessible. Society could allow a much fuller participation by a person with a mobility impairment by changing the environment. The extent to which it does not do so may be seen as disabling.

Reflecting this view, the term 'disabled people' is widely used in official and other publications in the United Kingdom, while the term 'people with disability' is avoided (Glasby and Littlechild 2009, p. 3). However, in Australia, the opposite is true. This appears to reflect the notion that all people have a complex set of traits (their preferences, jobs, hobbies, personalities) and that an impairment is just one aspect of their lives. For that reason, many people do not want to be defined exclusively by their impairment *or* the way society adapts to or exacerbates it. Accordingly, in this report, we use the term 'people with disability', which is customary in the Australian context.

Terminology aside, the key insight from the social model is that disability will sometimes arise from society's responses as well as from impairments themselves. Many submissions to the inquiry argued that this provides a strong policy basis for achieving the highest practical degree of social participation for people with disabilities and for giving them much greater capacity to exert power. (The importance of person-centred approaches to care and support is discussed in chapter 8.)

Nevertheless, while society can facilitate participation in the way it responds, there are limits in the extent to which it can achieve the full participation of every person, regardless of their traits. Society could not realistically be seen to have the capacity to eliminate the obstacles to participation faced by a person with extreme intellectual or behavioural disabilities. Accordingly, a more scientific approach to disability would see it as both a social and medical phenomenon, but for which an important social objective must be to facilitate participation in the various aspects of community life where practicable.

Moreover, societies have scarce resources, which means that there must be tradeoffs between what can ideally, and what can actually, be achieved for any person. There

are costs associated with making social changes to improve the lives of people with significant disabilities and, given resource constraints, these costs have to weighed up against other social objectives of a society.

Accordingly, as in many other areas of social policy — public housing, income support, health care and education — there are reasonable limits to what government or society can do to address inequality. However, it is widely accepted in Australia that governments and society must increase resourcing for disability and that they should address discrimination where it arises (for example, turning down a person for a job because of a disability not related to their work competence).

The United Nations Convention on the Rights of Persons with Disabilities

These issues are also the concern of the United Nations Convention on the Rights of Persons with Disabilities (box 1.3). Many submissions to this inquiry pointed to the importance of any new scheme adhering to the principles and obligations contained in that Convention, which Australia has ratified.

One participant observed that 'ratification carries with it much more than mouthing the sentiments and writing the high sounding statement into a glossy document':

> As noted by the UN Convention handbook for parliamentarians, '... establishing a right is not the same as ensuring that the right is realised', and neither is it the same as States providing, ... 'appropriate enabling environments so that persons with a disability can fully enjoy their rights on an equal basis with others'. … … simply being a party to a convention is no guarantee the intent of the convention will be realised. … if the report is to ensure the UN Convention is written into the NDS then the NDS must also ensure that an entitlement to service is ratified. (JacksonRyan Partners, sub. 30, p. 11)

In a similar vein, the National Disability and Carer Alliance said that, while ratification was 'an historic and significant moment', it was:

> … simply a first step on a long journey to ensure the rights enshrined in the convention are not only protected but, more importantly, able to be fully realised. While it is clearly not the only factor to be considered, it is important to acknowledge that rights can remain elusive if adequate resources are not provided. (sub. 413, p. 2)

Similarly, Catholic Social Services Victoria said that the United Nations Convention urges Governments to be proactive in identifying need and establishing more effective social support systems (sub. 453, p. 6).

Box 1.3 The United Nations Convention on the Rights of Persons with Disabilities

The Convention on the Rights of Persons with Disabilities and its Optional Protocol entered into force on 3 May 2008 (with Australia ratifying shortly afterwards).

Guiding principles of the convention

There are eight guiding principles that underlie the convention:

- respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
- non-discrimination
- full and effective participation and inclusion in society
- respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
- equality of opportunity
- accessibility
- equality between men and women
- respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

The convention states that persons with disabilities enjoy the same human rights as everyone. Without being exhaustive, these rights include equality before the law without discrimination, the right to live in the community, and the right to education and work.

The convention entails certain obligations on parties ratifying it, such as adopting legislation and administrative measures to promote the human rights of persons with disabilities, eliminating discrimination in workplaces and society; providing information to people with disabilities, undertaking disability-relevant R&D and appropriate consultation with people with disabilities in developing and implementing legislation and policies and in decision-making processes that concern them.

The goal of achieving equal rights is tempered by two considerations: a resource constraint ("With regard to economic, social and cultural rights, each State Party undertakes to take measures to the maximum of its *available* resources") and their progressive, rather than immediate, realisation.

In September 2009, Australia ratified an optional protocol to the convention which provides for a complaints handling process for people considering that their rights have been violated.

Source: United Nations (2006).

A commonly-held view was expressed by the Association for Children with a Disability NSW, which said that the current disability system is in violation of the United Nations Convention, 'if not in letter, then certainly in spirit':

> We believe a National Disability Insurance Scheme will go a long way in addressing this. Our children are our future — including disabled ones! (sub. 297, p. 11)

Clarifying 'supports' versus 'services'

Different terms are used to describe the services and supports that are provided to people with a disability. In some instances, the terminology differentiates between services and supports.

For instance, sometimes the term 'services' is used to denote therapeutic services only (such as health care, physiotherapy and other interventions of this kind). Such services often do not involve much choice by the person with a disability. Some see these services as things that are 'done to people'.

In contrast, the term 'supports' is often used to describe measures that, combined with the person's own goals and motivation, makes it possible to live as full a life as possible. Supports are not 'done to people', but with them.

The underlying distinction between the idea of 'doing to people' and 'doing with people' is critical to an appropriate disability care and support scheme (and is a major reason for providing people with disabilities much more choice in a new system). However, while that distinction is a critical one, using the terms 'services' versus 'supports' to differentiate between the two approaches runs up against the common use of the word 'services', which does not usually carry any sense that people getting them lack power.

Accordingly, in this report, the Commission uses both terms, with the term 'services' used most commonly when referring to agencies that provide specialist services, such as attendant care or respite services, or when referring to mainstream services, like going to a movie. That usage is common to other reports on the disability sector, such as the annual review of government services (SCRGSP 2011) and the various reports by the Australian Institute of Health and Welfare. It is also common for providers of supports to be referred to as specialist service providers (for example, in the National Disability Agreement between the Australian Government and state and territory governments). Many submissions to this inquiry used the term 'services'.

However, the Commission draws particular attention to the distinction between disability support organisations (DSOs) and specialist service providers. The former are intended to provide support to people in using services — brokering, managing administration, mentoring and planning — and the term 'support' provides a useful way of distinguishing their role from that of traditional service providers.

1.4 Rationales and objectives

Various forms of care and support for people with a disability have long been a feature of the Australian social support system. Governments seek to enhance the quality of life and increase the economic and social participation of people with disabilities and their families, and to enhance and protect their rights. Those goals are reflected in a range of social, economic, regulatory and spending measures. These include equal opportunity regulation, building and other accessibility regulations, community education and — the key issue for this inquiry — the provision of care and support for people with disabilities and their families. This inquiry reflects the Australian Government's intention, as stated in the terms of reference, to explore better ways of meeting that goal, including perhaps through the creation of a new long-term disability care and support scheme.

The key rationales for a new approach stem from faults in the current system

In part, interest in a new approach has arisen from an awareness of the faults in the current system, which are documented in many submissions to this inquiry and covered in greater detail in the next chapter. Broadly, these are:

- There are insufficient resources and gaps in services in all jurisdictions and most locations, so that people with disabilities and their informal carers bear too much of the costs associated with disability.
- People with similar levels of impairment get quite different levels of support, depending on their location or the origin of the disability — what some call the 'lottery' of access to services.
- Under the current provider-centric model, the capacity for people with disabilities or their families to exercise choice about the services they use, and to have control over the financial resources allocated to them, is limited.
- Services are largely narrowly prescribed and lack participation goals, and there are insufficient opportunities for employment or participation in the community.
- People with disability and their families often do not have a reasonable level of certainty about the future (a particular concern of carers of children with a profound disability, who often worry about how their child will be supported when they get too tired, sick or die).
- There is a lack of coordination, showing up through duplicated and inconsistent assessment methods for allocating services or funding, inadequate links between

services provided by different governments, and insufficient information for planning and coordination.

- There is lack of portability of services between jurisdictions as people move.
- There are also some inappropriate models of support, such as care for young people with disabilities in aged care homes and people remaining in hospitals — and therefore blocking beds — because of insufficient funds for relatively minor home modifications.

There are strong grounds for governments to improve care and support arrangements for people with disabilities and their families. It is consistent with:

- community norms for upholding people's rights and for social justice, which are not fully recognised in current arrangements
- sharing the costs that fall on people with disability and their families among a wider group of people — through some form of social insurance — and the low likelihood that private insurance markets would function equitably or efficiently in this area
- the desirability of unlocking a poorly utilised source of productivity and social contribution (for example, through employment and community participation).

But the key test of a new scheme will be the extent to which it can address existing deficiencies in an equitable, efficient, cost-effective and accountable way.

Objectives

The shortcomings of the current system bring the objectives of a new system into sharp relief. The overarching objective should be, to the extent practicable, to enhance the quality of life and increase the economic and social participation of people with disabilities and their families. As shown throughout this report, current disability services are not meeting the needs of people with disabilities and their families. There is a widespread need for arrangements that will deliver better outcomes for clients, with services and support more readily and uniformly available and driven more by the preferences of the client. A key question is how to build a better scheme that supports and empowers people with disabilities by:

- providing long-term support for all forms of disability for those most in need, irrespective of the cause and who is at fault
- meeting the needs of people with disabilities and their families in ways that are timely and efficient
- providing national standards for assessment of need and provision of support

- providing a much greater role for decision-making by people with disabilities (and their families where appropriate and necessary)
- providing incentives for cost-effective delivery of support services
- making it sufficiently well-funded to provide timely assistance to all who need it, without unreasonably long waiting lists
- ensuring it is financially sustainable over the long term.

However, an objective is only genuinely useful if governments know whether they have succeeded in achieving it. This requires specific and assessable objectives and the means by which progress can be assessed (table 1.2).

Given the multiple objectives for a disability care and support scheme, the relative importance of these objectives will be crucial in the design of an effective scheme.

Nevertheless, it may be difficult to *fully* meet all the community's objectives of a new scheme, reflecting the need for any scheme to be financially sustainable and practical. There may also be tradeoffs between some goals. For instance:

- effective integration of support services may be costly if there is a large amount of supporting infrastructure required to do this, or significant implementation costs in changing from one type of approach to another
- giving people complete choice and power over the use of disability funding may raise accountability issues and may not always serve all people well
- more choice for individuals and families may also mean greater uncertainty for service providers and coordinators, possibly leading to less coordination and greater costs
- more broadly, governments face many other competing obligations — for example, in health care, education and infrastructure — together with the need to ensure that tax rates are set at fair and efficient levels. A new scheme which meets the above objectives is likely to entail a significant increase in funding for disability care and support. Given all the other competing claims on governments, it will not be possible to meet *all* the preferences of people with disabilities and their families.

1.5 Some design elements for a new scheme

There are many possible models for a national disability scheme. The models could vary in scope (relevant users, types and levels of support, generosity and duration), funding sources, decision-making arrangements and governance.

Table 1.2 **Objectives and (some) indicators**

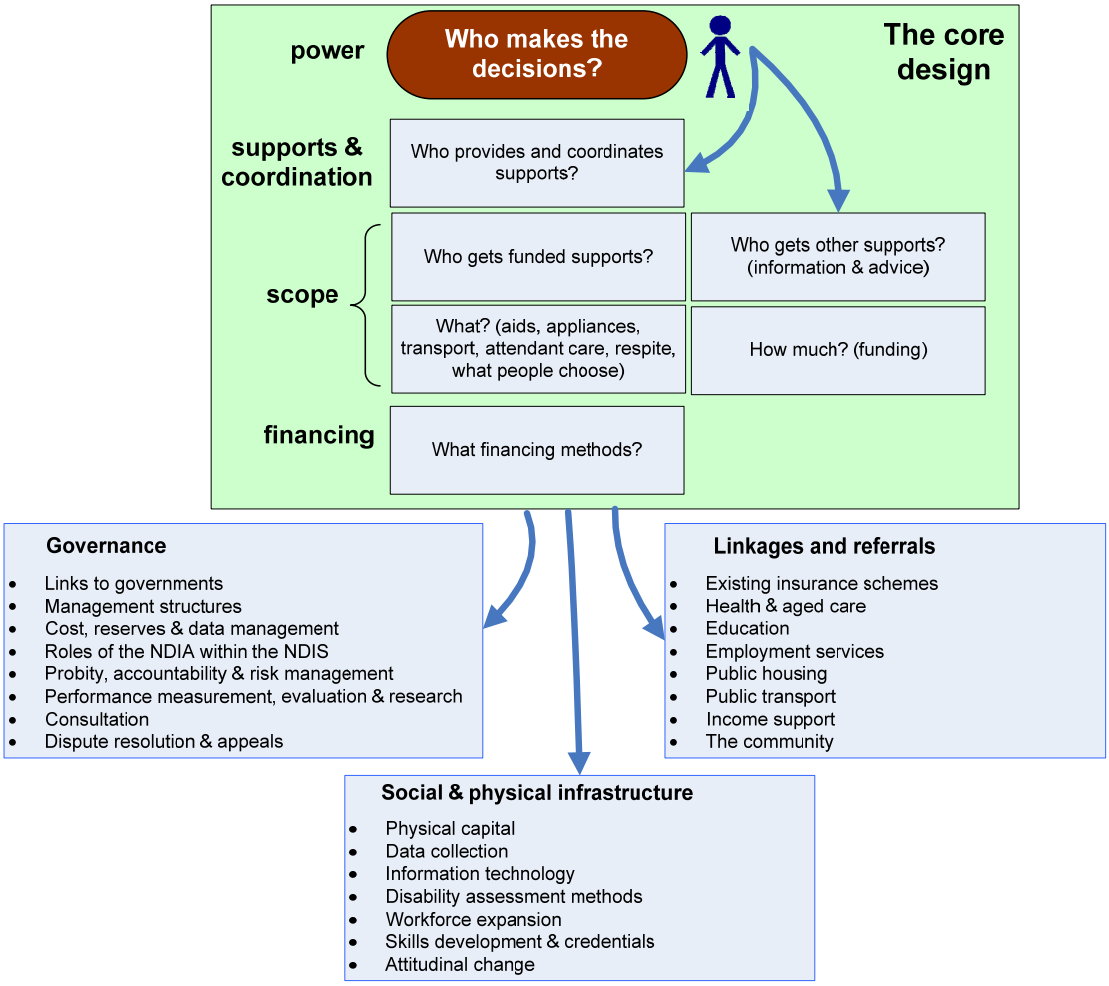
Objectives		*Some indicative measures of progress*
To improve wellbeing through funding of more integrated, higher quality support — including appropriate early intervention, and measures to lower the incidence and impact of disability	→	Improved consumer satisfaction, better continuity of support, higher social and economic participation rates, lower disability rates, reduced duration of some disabilities, lower hospitalisation rates for some disabilities
Ensure that people's assessed reasonable needs are met in a timely way as they arise, with predictability of support over their lifetime	→	Measures of support provision, unmet need, waiting lists, sustainable financing approach
Provide more comparable long-term care and support to people with similar levels of disability, regardless of the source of disability or the location of the person	→	Lower regional and state variations in support service access rates by all disability types
Provide people with disability more appropriate levels of power over their lives, and specifically over the budgets allocated to them, and with choice of providers	→	An appropriate capacity to self-direct funding (and its uptake) and to choose providers; consumer satisfaction rates with control and choice of services
Provide people with disability with better options for education, jobs, independent living and community participation	→	Participation rates in education, employment, volunteering, sports; consumer satisfaction rates with living arrangements
Shift away from an excessive and unfair reliance on the unpaid work of informal carers	→	Greater share of hours from paid support; greater independent living rates, lower depression rates and higher participation rates among carers; lower respite bed block rates
Effective management of the scheme, including cost-effectiveness and sustainability	→	Improved technical efficiency, higher support service utilisation, lower rates of multiple assessments, savings on future costs, low management costs, lower number of assessment delays, cost-effective use of new technologies, dispute and mediation efficiency, long-term scheme sustainability

One option is to substantially increase disability funding, but otherwise largely preserve the current arrangements. That would have many beneficial effects, but it would fail to overcome many of the structural deficiencies of the current arrangements. Given this and our terms of reference, the inquiry has focused on designing a coherent national system for disabilities.

As in health and aged care, there are many choices about how to design a disability care and support system. The core issues relate to who makes the decisions, who

gets supports, what supports they receive and the associated funding amounts, service delivery and financing methods (figure 1.1).

Figure 1.1 **Key design elements of a disability care and support scheme**



But realising a practically implementable and efficient scheme requires detailed attention to many other aspects of its design. Assessments of disability must be made (how?), the system must be organised and monitored (by whom?), linkages to related services and policies have to be identified and managed (which ones and how?), resources have to be built up (which ones?) and so on.

Failures in any one of these areas can undermine the capacity of a scheme to work well or meet people's reasonable expectations. For example, poor cost controls and risk management would limit the sustainability of the scheme, while a failure to consult with, and give more decision-making powers to, people with disabilities and their families would be contrary to the goal of enhancing people's independence.

These matters are discussed in detail in the relevant chapters throughout this report.

1.6 Inquiry processes

To help inform the approach taken in its issues paper, the Commission held early consultations with many people and organisations, including people with disability, carers, service providers, peak bodies, insurers and governments. These consultations provided insights into the key issues that would be involved in designing new arrangements for long-term disability care and support.

The Commission also held early discussions with the Independent Panel established by the Government to advise it and the Commission during the course of the inquiry (FaHCSIA 2010g). The panel comprises people with extensive expertise and knowledge of disability issues, and the Commission has continued to meet with the panel at frequent intervals during the course of the inquiry.

These early discussions also informed the Commission about appropriate ways to engage with people with disabilities and to make it as easy as possible for them to participate in the various stages of the inquiry (including making submissions and appearing at public hearings). The Commission is particularly grateful for the assistance provided to it on this matter by the Department of Families, Housing, Community Services and Indigenous Affairs.

In May 2010, the Commission released an issues paper to inform people about the key issues being examined and to advise them how best to provide their views to the inquiry. Participants were invited to send in formal public submissions, and/or to provide the inquiry with confidential responses outlining their personal circumstances and views. At the same time, the Commission released a short paper, together with Easy English and Auslan versions, which contained questions to elicit views about the desirable features of a national disability scheme.

We held initial public hearings in Hobart, Melbourne, Adelaide, Canberra, Brisbane, Sydney and Perth during June and July 2010. In total, people made 119 presentations over 12 hearing days. Participants did not wish to attend hearings in Darwin in response to the issues paper, but the Commission visited the Northern Territory following the release of the draft report to engage with a range of stakeholders. Consultations were held with a wide range of interested parties, including regional services and some Indigenous services. These are listed in appendix A.

The draft report was released on 28 February 2011. It contained the Commission's analysis, conclusions and draft recommendations as at that time, as well as requests

for feedback on particular issues. The draft report was distributed widely and made available on the inquiry website for downloading in whole or in part.

During April 2011, the Commission held a second round of public hearings to allow participants to respond to the proposals contained in the draft report. Hearings were held in Hobart, Melbourne, Canberra, Brisbane, Sydney, Adelaide and Perth, with 118 presentations over 11 hearing days.

Transcripts of the proceedings at all public hearings held during the course of this inquiry can be read on the inquiry website, and will remain there indefinitely.

Public involvement in this inquiry has been very extensive. Over its course, the Commission received more than 1000 public submissions, about half of which were from private individuals. This includes some personal submissions where the author was willing to make the submission public on a 'name withheld' basis. Many submissions were from people with disabilities or their carers. Also well-represented are the large and small organisations that support them. All public submissions can be read on the inquiry website, and will remain there indefinitely. In addition, the inquiry also received over 100 personal responses and completed Easy English questionnaires. The Commission thanks all those who have contributed to this inquiry. The information provided by participants was invaluable.

The Commission also wishes to thank the following organisations, which provided advice and data to the Commission on many occasions:

- the Accident Compensation Corporation (New Zealand)
- the Transport Accident Commission (Victoria)
- the New South Wales Lifetime Care and Support Authority
- National Disability Services
- the Australian Bureau of Statistics
- the MS Society of Australia
- Ageing, Disability and Home Care, Department of Human Services (NSW).

The Commission also thanks Vision Australia for assisting it to produce accessible documents for its website.

1.7 Structure of the report

The report begins with an introduction (chapter 1) and a discussion of why change is needed. Many participants (including providers, people with disabilities, carers and governments) think that disability services are often in crisis mode, with fragmented programs, inadequate provision of services and high levels of unmet demand. They argue that whether people get good services can be a 'lottery', based on where they live and how they acquire their disability, and that people often have little choice about what services they receive. These matters are discussed in chapter 2.

Chapter 3 looks at which groups of people would use a National Disability Insurance Scheme (NDIS) and how they would be referred to other services and supports as needed. The following five chapters look at how people with disabilities could interact with the NDIS. This includes the role of the community and community organisations (chapter 4), what support services people with disabilities should be able to get access to (chapter 5), how the Disability Support Pension might be aligned with the goals of the NDIS (chapter 6), how people would be assessed for assistance (chapter 7), and the question of who should have the power to decide what supports people get (including the role of person-centred approaches) (chapter 8).

The governance of the NDIS is considered in chapter 9, while the implications for service delivery are covered in chapter 10. Chapter 11 focuses on Indigenous issues, given the higher rate of disability in the Indigenous community compared with the broader population, their low rate of claims for some forms of services and supports, and the particular difficulties of delivering these in some areas.

As many clients of the NDIS will have various care and support needs over many years, it is crucial that the long-term financial viability of the scheme be a key objective. Good quality data and evidence will be crucial in managing the scheme's costs, learning about the efficacy of alternative services and generating good outcomes for people with disabilities. This is the subject of chapter 12, while the specific question of the appropriate use of early intervention strategies is discussed in chapter 13.

The following three chapters examine how the NDIS might be financed (chapter 14), workforce issues (chapter 15) and estimates of the likely cost of the scheme under different scenarios (chapter 16).

Many participants argued that there is little justification for the striking differences in current arrangements for insuring people for injury, with coverage varying

depending on the type of accident, its location and exact circumstances. Chapter 17 looks at the advantages and disadvantages of the current accident insurance arrangements, including the role of common law claims. Drawing on this analysis, chapter 18 proposes a National Injury Insurance Scheme, and discusses how it might be financed.

The measures proposed in this report are very significant and will require considerable care in their implementation. The national rollout of the scheme would require the Australian Government and all state and territory governments to be involved. And some changes would need to be sequenced. These matters are discussed in chapter 19. The final chapter looks at the benefits of making changes along the lines recommended in this report.

In preparing this report, the Commission has written several appendices, but only one, that concerning consultations undertaken (appendix A), is reproduced in this report. The remainder can be read on the inquiry website at www.pc.gov.au under 'projects'. A full list of appendices is contained in the table of contents.

The structure and performance of the current system is not covered in this report in great detail because comprehensive up-to-date descriptions by the Australian Institute for Health and Welfare (AIHW 2009b, 2010a) and the Steering Committee for the Review of Government Service Provision (SCRGSP 2011) can be readily accessed.